

FAS.TIMES

FETAL ALCOHOL SYNDROME / FAMILY RESOURCE INSTITUTE NEWSLETTER

The Legacy of *FAS Times*

Jocie DeVries

In January 1991 the Adoption Support Program manager asked me to write a letter to families in Washington State about our experience raising a teenage son diagnosed with FAS. I felt an enormous burden of responsibility in accepting this task, but I did write the letter and this communiqué was the precursor of *FAS Times*.

A few months before that (September 1990), I had decided to go back to school, to major in journalism. Not understanding our son's disability, I entered college at the same time that he entered high school. As I naïvely labored to hone my writing skills, my son, Russell was growing into a teenager who was over six feet tall. With his new-found adolescent energy, he was driving us crazy, flexing his wits against parental authority and striking out for independence. The problem of course was that he had more intelligence than anybody should be allowed to have at that age, but he had the full dose of impulsivity and unpredictability of FAS. And to make things even worse, he had all the creativity and ingenuity of MacGyver (the star of the hit TV show of the same name).

The reality of dealing with the chaotic situations Russell brought into our lives, seriously strained the relationship between my husband and me. The police were at our house almost daily, as we tried to cope with Russell's antisocial behavior. My husband and I felt humiliated and embarrassed; but unfortunately, Russell did not. My husband—as the only breadwinner in the family—kept telling me that I had to drop out of school to manage the chaos at home while he was at work. I was not a happy camper about the idea to say the least; but as the seriousness of the situation sank in more and more with each new crisis, I dropped one class after another. But I absolutely refused to drop my English class.

In November Russell was arrested for starting a fire in the dumpster at his school while I was at the college. After his arrest, I knew I had no choice but to drop out of school. I was devastated as I walked into the administration building that day. Mired in self pity, I filled out the paperwork and dropped my English class. Afterwards I dejectedly started walking toward the front door that led out to the parking lot when I heard a voice say, "Turn around and go to the back office and talk to that woman over there."

Immediately and without thinking, I made an about face and started walking toward a glass-enclosed office. I had never experienced any such message before (this conversation took place deep in my mind). Suddenly I realized that what I was doing had no logic. I caught myself and exclaimed to myself, "Are you crazy? You don't even know that woman!"

Whipping around, I headed for the door again and that's when I knew I was hearing the voice of an angel because there was no logic to what I was doing. Again the voice was firm, "Go in there and talk to her." Automatically, I did another about-face. This conversation continued for a few seconds with me walking one way, following directions and then walking the other way to leave the building. Finally I said, "OK, OK! I'll go in there, but I have no idea what I'm doing and I'm going to look really stupid."

As I walked into the glass-enclosed office, I walked hesitantly up to the receptionist and asked her if I could see the manager. The receptionist told me, "Today isn't a good day; she's really busy." I didn't know what to say except to tell her that it was really important. She sighed, looked at me and then got up and went into the inner office. When she came back, she said that the manager had agreed to see me for a few minutes.

As I walked in, I still didn't have a single clue as to what I was supposed to be doing, but I sat down anyway. I began stammering and then hemming and hawing. Finally I mumbled something about how depressed I was at having to drop out of school and then I mentioned something about Fetal Alcohol Syndrome.

Suddenly, the woman started to sigh and take deep breaths like she was struggling to make a difficult decision. Startled I thought, "Uh-oh. What's going on here?" Then I knew this was a divine appointment

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Our Board: People of Commitment & Loyalty

FAS TIMES

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• Editor & Publisher

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• Editorial Board

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and that I'd better keep talking and keep her engaged in conversation, to see where it was going.

Finally, she sighed again and said, "Well, I'm not really supposed to do this but I have a friend, Roxanne, who is also raising an adolescent with FAS and I'm going to give you her phone number." I nearly fell off my chair I was so shocked. As a result, Roxanne became the first parent I ever talked to. She taught me how to look at the humorous side of FAS so well that I never laughed so hard in my life. Our boys were about the same age and he too kept getting arrested, just like Russell.

The first time I talked to her, she told me that someone had taught her son how to hot-wire a Toyota and thus far he had stolen six cars. She didn't know what she was going to do with him. He never stole anything but Toyota's because he couldn't generalize this skill to figure out how to hot-wire any other model of car. A few weeks later I talked to her again and by then he had stolen eleven cars. Then it went up to twenty-two. The last I heard, he had been arrested for stealing a total of thirty-six Toyotas.

The strange part of the robberies though—and what puzzled the police the most—was that no matter how many times he was arrested, he continued to do the same thing again and again. He would hot-wire a car, drive it home, park it in his mother's driveway, then come in and go to sleep until the cops arrived.

FAS Times began a few months later as I struggled to describe FAS to the families on the Adoption Support mailing list. The point of this story is that the journey of the FAS Family Resource Institute to gather, analyze and share the Collective Family Experience on FASD began with an angel's command.

A miracle connected me to Roxanne. And now many years and miracles later, I enjoy wonderful and blessed friendships with many of you. *FAS Times* started with a little bit of sadness and a little bit of divine intervention and this too is the way it is coming to an end with this final issue.

I am deeply grateful to the leadership of the Washington State Division of Alcohol and Substance Abuse (DASA) for the opportunity to publish *FAS Times* for over thirteen years. Recently, however, NOFAS Washington contacted DASA about our sole source contract. Evidently, even though our contract was given to us by DASA in 1995 as a sole source contract (meaning we were/are the only ones

who can provide the product), sole source contracts are not guaranteed, according to DASA, if another agency presents itself and is able to provide "like services." As a result, the contract was split and we are losing the funding that supported the ongoing production of this newsletter.

As we were completing this, our final issue, I realized that we have essentially produced a 672-page book (if it were put into book form) that documents the FASD Collective Family Experience. This whole body of information and wisdom of practice contained in these "pages" has been preserved and is archived in our offices. Our plan is to make PDF's of the back issues of *FAS Times* so we can make them available to everyone on our website and thus preserve this whole unique and historic body of information. PDF's of the issues from the last two years are already posted on our website at: <http://fetalalcoholsyndrome.org/times.htm>.

So as this specific chapter in the story of FAS*FRI comes to a close, I want to say thank you to all of our readers for your ongoing encouragement and support in our efforts to document and share the Collective Family Experience on FASD through this newsletter. It has truly been a challenging and rewarding task.

A few weeks ago I had a very interesting experience. As I was recovering from my six-month bout with chemotherapy, I had another visit from an angel, but this time it took place inside a dream. In the dream I was in a dark, lonely and dreary place. But as the dream progressed, I started thinking about all the wonderful, crazy, funny adventures we've shared while creating *FAS Times* and I started laughing. Gradually, the environment of the dream started getting lighter. The air began to swirl with twinkling, iridescent, pastel colors—much like the images of the northern lights—and I realized that the light represented the angel. I felt warm and happy, surrounded by perfect peace. Eventually the swirling light touched my lips and the angel said, "It is finished."

It is important to remember, however, that even though *FAS Times* is our most well-known product, it is not the sum and total of what we do here at the FAS Family Resource Institute (FAS*FRI). Our mission is to help others identify, understand and care for those with FASD and their families and to prevent future generations from having to live with this disability. *FAS Times* is just one of our

educational products that have been funded by DASA since 1995.

The good news is that the funding for several of our other major projects will continue. We would like to thank Doug Allen, DASA's Director, and Sue Green, our contract manager, for their continued support and funding of these other products: our toll-free information, mentoring and referral phone line; our website; and our Intervention Touchpoint Trainings on the FASD Behavioral Phenotype from the Collective Family Experience. We are happy that we will be able to carry on **these activities** because they **are the broadest avenues where we can help affected children, their families and the professionals who serve them in practical and concrete ways.**

Now that the state of the FASD field is in the process of catching up with the desperate need of families for a diagnostic method that is not solely dependent on the face, we can start to relax and turn our attention to creating public awareness projects that focus on sharing interventions that have been successful for our (now) adult children. This brings us to the second piece of good news: we are announcing the upcoming creation on our website of the FASD Family Preservation Blog. We are really excited about this education initiative because preserving family relationships is at the heart of all we are and all we do.

One of our charter board members, Delinda McCann, has graciously agreed to volunteer her time to moderate this blog. She will be a great fit for this responsibility and will carry it off with a great sense of humor as demonstrated in her article, "Going Greener" on page 3.

In this issue of *FAS Times*, I want to introduce you to some of the faithful officers and board members of FAS*FRI. (See p. 11.) The other day, I added up our collective years of experience in caring for our children, youth and adults diagnosed with FASD and it totaled over 400! By the grace of God, all of these affected individuals are alive and none of them are incarcerated, at least as of today ☺. Most of them are now adults and they are successful as we define it by living healthy, safe and happy lives. We will be sharing the interventions that have helped them be successful on the **FASD Family Preservation Blog**, which will be available on our website beginning August 1, 2008. I invite all of our readers to check it out at <http://fasblog.fetalalcoholsyndrome.org>. ♥

FAS*FRI: Going Greener

Delinda McCann

It isn't easy being green. Kermit the Frog

Once upon a time, the only one concerned about being green was Kermit the Frog and possibly Frank Sinatra. Shortly thereafter, the FAS Family Resource Institute was born. Like many newborns the Institute had no property and no money. As a matter of functionality, we were born green. Nobody commuted to work because we had no office. We used very little electricity because Ann and I were the only ones to own computers, assuming a 4-meg hard drive could be called a computer. One hot topic of debate was whether or not to allow Jocie to have a word processor or whether this would create too many technical problems for her and thus for us.

With the formation of our 501(c)3, people began to ask where we would locate our office. Jocie who was collecting copies of everything written on the topic of FASD began to think longingly of a central library. While she dreamed of getting rid of the boxes of paper that were collecting in her spare bedroom, the rest of us sadly resolved that when the "office/library" arrived we would not be able to be active in FAS*FRI because we still had kids with FAS at home. No way could we leave home to go to an office, at least not without a major staff meeting with nine other people to care for our kids every day.

The light dawned for me when I learned a new word, "telecommuting." The rest of the staff said, "Tele...what?" I explained that it was the right word for what was evolving at FAS*FRI. We did not need an office. We had no money for one and most importantly a central office would be totally impractical. Vicky had visions of a quiet cubicle with a receptionist who could be instructed to not put through any calls from her kids, their schools, coaches or friends' parents. But these were clearly wild fantasies.

Thus FAS*FRI was born as a telecommuting institution. Our workers spent no time or gas commuting to the office. Those resources went directly to advocacy work. In the beginning communication remained a problem. Remember nobody had cell phones back then. Our answering services were tape recorders and the tapes were always full by the end of the day. A turning point in our efficiency came when Jocie

was given a FAX machine and Ann set it up for her. Vicky had gotten a computer by then, so we could now all send written material to each other.

The down side of this occurred when my Mac started having an affair with Jocie's FAX machine. Jocie would get up in the morning to discover pages and pages of paper containing what she surmised to be hot steamy computer language, all from my computer. At least my computer was carrying on this affair at 1-2 am when the phone rates were down, but to save money it became necessary for me to unplug Mac, a sad step along our path to greenness.

The arrival of the internet, called the "world wide what?" by the FAS*FRI staff, solved a lot of the problem of information storage, although Jocie still has many boxes of carefully hoarded papers in her garage, perhaps even some of Mac's letters to her FAX. So this problem has continued to plague her husband who would like the space for his cars.

Technology and relative poverty have driven the development of FAS*FRI as an organization that uses few resources and as a side benefit produces a small carbon footprint. As we have grown accustomed to each other's work styles, we find no need for staff meetings. We've morphed into an efficient team. A few e-mails such as "Delinda, we really need that article from you now. Come on, we know you can do it!" convey everything that needs to be said for organizational purposes. I know what I am supposed to do, as does the rest of the team. We each have our international network of advocates, politicians and parents who keep us up to date on what is happening with their organizations. By simply hitting forward, I can let the rest of the team know what is new in England or at Olderfas (an e-mail list serve group). We can track trends and repeated problems.

Lately, those repeated problems and trends have begun to bother me. I feel as if I am shouting, "Hello, out there! Is anybody home?" and I am not getting an answer. Part of my disquiet may be due to the fact that our current network has outgrown our ability to respond. What to do? Go Greener!

As in the past, financial needs have pressured our meager budget. A large part of our funding was cut. Jocie, Vicky and Ann put their heads together and asked the question as

to where we could cut. Ann, the *FAS Times* editor, has been feeling called to expand her horizons. The decision to discontinue the publication of *FAS Times* seemed a natural, albeit sad, decision.

Then we had a party. Staff meetings are highly overrated. Go for parties instead. As we were laughing and telling funny stories about past adventures, I thought I'd try something new out on the team and mentioned a BLOG. Hey, they knew what I was talking about! There is hope that we may conquer the disability called FASD. If we can cure Jocie's techno-phobia, we can do anything. Jocie said she had also been thinking about a FAS*FRI blog. I listed among the advantages of the blog an elimination of paper usage, the cost of postage, and that going electronic was greener. This was when we began to fully realize that we have always been "green" because it works and it will continue to work. So here we are now, going even greener—introducing, *The FASD Family Preservation Blog*. I see the blog as a more efficient means of continuing the work of *FAS Times*. We want to continue our message of hope and healing for families living with the chaos called FASD. We plan to have parents and specialists contributing. Perhaps Ann, now that she is free from her editing duties, will have time to write about some of what she has been learning about wholeness, health and healing. While we want to continue to hear from those who have written for *FAS Times* we are looking forward to the opportunity for feedback from a wider audience.

I hope to get enough feedback that I will have to limit how much of it I can post. While I do enjoy writing, I am also content to let others do some of the work, so feel free to comment. The blog will be limited to articles of general interests rather than solving problems for a specific person.

Existing support lists and other web sites cover the topics of specific problems and share research posted or printed elsewhere. We do not want to duplicate the work those groups are doing, but we would be happy for a report on topics that people think are worth the attention of the researchers or anything that has proven to be an efficient successful intervention. I hope the blog will grow and change as the medium matures and we continue to learn more about preventing FASD and caring for those who live with this disability. Please come visit and join with us in our newest green venture at <http://fasblog.fetalalcohol syndrome.org>. ♥

\$25 Million for What?

Victoria McKinney, FAS*FRI Co-Director

In late 1997, four of us (Ann Waller, Dorothy Beckwith, Jocie DeVries and I) arrived in our nation's capitol city on what we assumed was a mission of mercy. We were in Washington, D.C. on behalf of FAS*FRI parents raising affected children. Among our board members, we had over 400 years of experience caring for diagnosed children. And as such, we introduced federal lawmakers to the Collective Family Experience on FASD. We received such a warm reception from members of the House of Representatives and the U.S. Senate that it seemed as though we were in a dream.

We were so full of optimism and hope talking about the needs of individuals and their families. They respected our expertise and listened to our requests. The experience was awesome, emotionally overwhelming and darn exciting. We were just moms on a mission talking about the needs of our kids. There was one Senator in particular that already understood FAS, Senator Tom Daschle. After we explained about the unmet needs of families, he tried to make a positive difference. After hearing about the Collective Family Experience, his staff apologized that they had not had any input from families raising affected children on the original bill and they asked us to help them revise it to make it more sensitive to families.

We worked with Senator Daschle through his remarkable aide, Ellie Dahoney, as they rewrote the bill. He introduced it early the following spring and after we found a bipartisan sponsor, Senator Slade Gorton from Washington State, the first FAS bill passed into law in the fall of 1998. The appropriation for it passed two years later in 2000. Because the bill had bipartisan support, it was paired with a twenty-five million dollar appropriation. **Imagine our naïve joy as we envisioned 25 million dollars going to families for support services.** Unknown to us there were ominous clouds on the horizon: when money becomes available, bureaucrats and professional grant writers gather.

This federal legislation on FASD was signed by the president and its appropriation passed into the U.S. Department of Health and Human Services who gave the assignment to one of their smaller agencies, the Substance Abuse and Mental Health Services Administration (SAMHSA). It was their job to implement the legislation. As is often

the case, SAMHSA sent out a Request for Proposals (RFP) to build a national center of excellence for FASD.

To our dismay, the RFP was not awarded to a university with expertise on FASD but to something called a beltway bandit. As explained in Wikipedia, **beltway bandit** is a term for the private companies located in or near Washington DC, whose major business is to provide consulting services to the US government. As explained by a taxpayer: Beltway Bandit is an entity that knows nothing of the issue but has a great grant writing team that meets all the federal criteria of a grant and takes a huge percentage of the funding, often in excess of 50%, for administrative costs and little of the funding actually goes to solve the problem.

In the case of the Congressional appropriation to help those with FASD, Northrop Grumman, got the contract to develop and run the FASD Center for Excellence. Even though we were stunned and disappointed that an airplane manufacture got the contract, we found a glimmer of hope in 2002 and 2003, when SAMHSA agreed to hold regional Town Hall meetings on FASD around the country. The 13 town hall meetings that FAS*FRI organized* in 2002 and 2003, were in states that already had volunteer family-run groups on FASD. The media interest was high as affected individuals and parents told their stories.

As Northrop Grumman began organizing to bring the FASD Center for Excellence into reality, I accepted a position on the Steering Committee, which I thought was a position where I could continue to represent the needs of individuals whose diagnoses were not solely dependent on mental retardation or facial features. After all, we parents have been gathering this body of knowledge called the Collective Family Experience since 1990.

After attending six years of steering committee meetings in beautiful cities across America, I now understand the cynicism behind the old joke, "How many PhD's does it take to change a light bulb?" I have come to the conclusion that bringing practical help to the most deeply wounded victims of FASD, is not going to happen by and through committee meetings. And if we fol-

low the current leadership at SAMHSA and Northrop Grumman, another 25 million dollar appropriation from Congress won't ever get to families who need help either.

One of the most stunning issues to me that was never resolved during the six years of committee meetings that I attended was the clashing definitions of the word "advocacy" between families and bureaucrats. Why this stumbling block could never be resolved was so illogical. This issue was so representative of how little the federal government and the FASD Center for Excellence truly understand the implications of having the responsibility to care for and protect an affected child/adult.

To them the word advocacy rigidly meant lobbying Congress. Advocacy from the Collective Family Experience means intervening in the chaos to keep affected loved ones safe from addiction to alcohol and other drugs, safe from being warehoused in psychiatric hospitals, jails or prisons and helping them stay clean and sober so they won't produce the next generation of children with FASD. SAMHSA and the Center never understood what I was trying to say, so I was chastised for six years whenever I used the term advocacy. They told me I could call it "education" but to me their *blind-spot* only re-enforced my overall feeling that the staff from SAMHSA and the Center for Excellence never quite got the FASD concept at all. After all this money and time—the first \$25 million appropriation and 5 years—no support or funding was ever considered for the family-run "educational" groups, even though these groups were the main thing the town hall testimony said was "working."

For these reasons, I felt I had no choice but to resign from the Expert Panel. The following is a copy of my resignation letter I sent recently to the FASD Center for Excellence and the other members of the Expert Panel.

Effective May 17, 2008, I resign from the Expert Panel, FASD Center for Excellence. Although the reasons are many, the three most significant are outlined as follows.

- In the future, my energy and efforts will focus on FASD family networks and FASD grassroots organizations, whose commitment is focused on helping individuals with FASD and their families instead of building

* two additional sites organized their own town hall meetings

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Tributes to Jocie: FAS*FRI Founder, Master Advocate and Visionary

Awhile back, Vicky came up with the great idea to ask people to send in their thoughts and experiences of Jocie to honor her in this last issue of FAS Times. The following are some of the letters and notes we received. As the Editor, I decided to grant myself the privilege of writing the introduction.

I still remember the first time I talked to Jocie in late 1991. She was the only person I had talked to about our adopted son who understood what I was talking about. I remember her saying, "I'm so sorry that happened to you," and I knew she really meant it, even though she didn't know me.

Over the next few years, we came to find out that we had many things in common, including our faith. We began working together and our friendship deepened. I consider her my best-est friend, ever. I'm truly grateful that even though the path of raising our affected children has been a rocky one indeed, it has also brought some shining diamonds like Jocie into my life. Ann

Although Jocie has always been the "velvet hammer" and advocate for thousands, she is first and foremost a wife, mother and grandmother. We have been honored to feel the depth of her family commitment. The way she glances across the room at her husband Don, makes you want to fall in love again. Little did we know when we first met Jocie, what an amazing woman she was.

Her vision was and still is for every child with FASD to be loved, understood and treated with compassion. Her instinct always went much deeper than finding the next destination as we often heard, "Okay girls, we're safe because we've been lost here before."

She could dry the tears of a family in crisis, give them hope and turn around and stamp her lace stocking foot at a policy maker's door and send them scurrying for cover. What an amazing woman! We will be forever grateful for her guidance, her encouragement, her laughter and her friendship. We love you!

Linda and Vicky

I will always remember the day I met Jocie...I was attending a conference. Though my husband and I had been foster parents for a few years, I had never heard of the term Jocie was using, *Fetal Alcohol Syndrome*. Little did I know that our desperate prayers

were about to be answered.

We had recently adopted two children who had been placed in our care by the Division of Children and Family Services (DCFS). Parental rights had been terminated and the state assured us that we were just the family they needed to nurture them to 100% health. By the time of the conference, we'd become very concerned because it was clear our little ones were becoming more complex and challenging each day. We'd sought professional help, but so far nothing was proving to be very helpful.

As Jocie compassionately shared her adoption experience, I realized she was describing the very behaviors we were struggling to understand within our home! A MOM was giving me answers that no professional had yet been able to do. Joy and sorrow became interwoven and I found myself completely overwhelmed with emotions. Tears streamed down my face. I knew I had to meet and spend time with Jocie, but my emotional state caused me to be too embarrassed to approach her. As I've come to



learn is so typical of Jocie, her understanding compassion moved her to come to me.

By nature, I am a shy person. The love I had for my children helped me find my voice, but I still needed the courage and wisdom to use it in the toughest of situations. Watching Jocie advocate left me without excuse. Against great odds Jocie relentlessly pursued what was good and right and best for

our kids. Her leadership inspired each of us to advocate for appropriate care for our own children and the whole population disabled by FASD.

When crisis hit within her own home, Jocie showed with actions how to turn the experience into an opportunity to educate everyone involved. At times I watched her tremble, but she always held firm as she stood up to those who interfered with FASD advocacy efforts. *Never once did she give up.*

She has always been a force to be reckoned with, one who became affectionately called The FAS Pest of the West. Jocie never wasted energy banging on closed doors. She searched for open doors and once she found them, she would diligently make the best use of the time and opportunity before her. Jocie always had faith that a plan would come together. And it always did!

Love is a powerful motivator and Jocie has always generously shared her love with those who live with, care for, and work with those affected by FASD. Jocie has the gift of being able to put into words the behavioral traits our kids manifest. Her insight and intuition made sense when it came to explaining and understanding the impact FASD has on individuals and their families. She wisely knew to gather the collective family experience which further validated the behavioral phenotype caused by prenatal exposure to alcohol. Her leadership efforts have left the world a better place.

There is a place in my heart that will always belong just to you, Jocie. You are my hero. You are my angel friend.

Dorothy Beckwith

I met Jocie on the phone in June of 1990. My granddaughter, Chelise, was almost 2 years old and I was pretty frazzled with trying to meet her needs 24/7 and using every technique I'd learned over the years raising 3 boys. Not much was working!!! I really can't remember where I heard about FAS*FRI but I am so thankful that I did.

I called their number and a real person answered the phone. It was Jocie and she was WONDERFUL!! I didn't have to explain everything and then defend my position. SHE KNEW!! She knew my child; without ever

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Moving Forward in Peace and Hope

Ann Waller, M.Ed.

I have always been very thankful that Jocie and Vicky were the first-line people when it came to talking to families, hearing their stories, supporting them, giving them information and referring them to the appropriate agencies and resources. It's not that I don't care or even that I don't have anything to share with these families. I just couldn't do that day after day with so many families struggling with all their trauma and grief and living without services. I tried joining an FASD e-mail list serve a couple of times and got so overwhelmed with them, that I soon quit. My forte is writing, editing and teaching, so I pretty much stick to those arenas.

But there have been a few exceptions, a few moms with whom I've have a special connection and ongoing communication. I would like to tell you about one of them. I met Elisa, an amazing woman, at our retreat in August 2005. She came to the retreat because she suspected her young daughter had FAS, but she didn't have a diagnosis. We shared a similar faith and both of us felt an instant connection with each other at the retreat. We have kept in touch, exchanging several e-mails since then.

The first week after the retreat, she wrote, "Lady, you and Jocie lit a fire under me that even my husband can't put out! ☺ I see my child through completely different lenses and want the rest of the world to see too." In the same e-mail she revealed how fast and far that fire had taken her *in just one week*. Her e-mail continued, "I have an appointment to speak at a Foster Care/Child Protective Services Office for [our whole] county! My pastor also wants me to educate him. I thought I would create three PowerPoints (from the stuff I gathered from you guys) one for the educators in my child's life, one for the counselor types like at the Foster Care workers' office, and one for individuals who just want to know about FASD."

Like I said, amazing woman.

Then she asked me where to start in "this advocacy marathon." I told her, the best place to start would be to get a diagnosis for her daughter—which she promptly pursued. She succeeded too, after nine months of time, effort and expense, even taking her daughter several states away from home to an FAS clinic to get it.

The subsequent e-mails between us addressed various topics, such as the seizures her daughter had developed, depression as a possible co-occurring disorder, what mental health services might be helpful, etc. A couple of months ago, she wrote again with thoughts and questions about her daughter's future, including: "As a mom, and a Christian, I am asking you....Am I really being unrealistic? Am I misguided to think that I should set up a future for her, with checks and balances...or do I just trust that she has her God and her life is to be lead by her alone?"

Her questions brought up several important issues that many parents think about as their children get older, so I thought I would share my response with all of you.

Hi Elisa,

I'm so sorry your daughter has not received the services she needs. This happens so much with affected kids who have IQ's in the normal range, even with a diagnosis in hand. But you do have a couple of things on your side. You have figured out what works for her as far as schooling [she mostly home-schools her daughter] and you have a diagnosis before she has hit her teen years.

It's unfortunate that a diagnosis doesn't mean automatic eligibility for services, but it's the first necessary step and it can really help to establish the neurological brain damage, especially if the diagnosis is written up as such for the people who don't understand what it means. Did you get a copy of the diagnosis [in writing]? If not, request one. Keep the original in a very safe place and make copies to take to meetings and appointments. Did the doctor do a complete neuropsych assessment? If so, did you get a report on the results? If not, again, request one. This should give you more information/documentation as to the specific type of challenges she faces.

I'm not sure what services you are trying to get, but you have to learn the appeal process in each system and demand services in order to get them. Vicky works with many families directly, so she is up to date on the specifics in education especially. Feel free to contact her at vicky@fetalalcoholsyndrome.org. Does your daughter have any kind of IEP in connection with her activities through

the public school system?

If the system is Developmental Disability or Mental Health, each state differs as to their specific eligibility requirements. But you can request an application or assessment based on her diagnosis and then keep appealing until you get what she needs. One of the basic rules to remember in advocacy is that the first 2-3 people you talk to are only authorized to say "no." So you have to work your way up the chain of authority till you get past them.

Sometimes involving your state legislators can help if they understand your daughter really needs services and especially if you are being denied the right to apply or to appeal denials (which happens all too often). There are Parent Training and Information (PTI) groups in every state. They should be able to help you with CA laws, advocacy tips, etc. You can find who and where they are at: www.ed.gov/pubs/parents/Including/resptic.html. There is also a list of resources and organizations that might be helpful on the Wrights' Law website Yellow Pages: <http://www.yellowpagesforkids.com>.

I would not advise you to change any of your plans. I think it's great if you can help your daughter live and work in supported environments as long as she will agree to it. All of us want to keep our children safe as much as possible, disabled or not. Some parents are finding various levels of supported living situations for their affected young adult children through mental health departments. She may have to have other co-occurring mental health conditions to qualify or you might be able to prove she is a "vulnerable adult."

However, I would caution you to hold your plans loosely. As she becomes a teenager and a young adult, some of what happens is going to be dependent on her choices, how much she wants to be under your protection/authority and what she perceives are her "rights." (You may even run into professionals, like counselors, who feel it is their duty to let her know her rights, even if you believe she isn't capable of making appropriate decisions with that information.)

If she doesn't want to stay home and/or live in a protected environment, she will be

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The Linda Belle La Fever Un-ceremonial FASD Awards

"So," I asked, "an article for the very last issue of FAS Times, huh? What sort of theme would you like me to address?" The answer from my very best friend, Vicky McKinney, was: "You can say *whatever* you want to say." I thought to myself, "now that sounds like fun!"

With that in mind, I'll begin my own personal award presentation by honoring the heroes and saints who have moved mountains, built bridges and have been the binding force that has held families together when bureaucracy has trampled them and emotionally beaten them into the ground. At the core, on the front lines these are the birth parents, grandparents, foster/adoptive parents and extended family members who have unselfishly set aside their needs and goals in order to provide for a child or an adult child with organic brain damage caused by prenatal alcohol exposure. Due to the shameful absence of services for the disabled in this country, the majority of victims of FASD (those who do not have mental retardation, but are nevertheless profoundly mentally and intellectually challenged), their families and caregivers have been forced to mortgage their homes, sacrifice their retirements, cash in their life savings and seek employment at his/her local fast food restaurants in order to provide care for intelligent but vulnerable individuals. Every single day of their lives these dedicated caregivers hang on by their fingertips and bare teeth to the only support they know and trust—the Collective Family Experience. To these desperate but loving families, the unsung heroes, I bestow The Wind Beneath My Wings Award.

Oh my! The Collective Family Experience, that sounds like the foundation for all of the many publications that the FAS Family Resource Institute has created and made available to ANYONE who asked. Yes. Even sent FREE to MD's and PhD's who could well afford the requested donation. You know who you are.

My next award, The Tower of Power and Grace, goes to:

- Jocie DeVries: mother, FAS*FRI founder, advocate, visionary.
- Vicky McKinney: mother, FAS*FRI Co-director, warrior advocate, pest.
- Ann Waller: mother, teacher, word-smith, grace-filled survivalist.

- Delinda McCann: mother, powerful advocate, leader by sterling example.
- Dot and Susan: tougher than I'll ever be and power mothers to be admired and feared.
- Dorthy Beckwith and Pam Medgard: devoted mothers of impossibly disabled children, and the funniest dynamic duo in the west.
- Margie Booth and Kathy Dodson: gentle, quiet mothers who mind their own business while giving their absolute all.
- Georgia Gore: devoted mother bear, loving friend, defender of the most vulnerable.
- Bonnie Crawford: Jocie's sister, who had the patience of Job while helping me with my book, "Cheers!"
- Ann Streissguth: mother, research scientist, monarch, gentle spirit, honored woman.

But now let's get on with the really fun part of this column. Let's play, "Pin the Tail on the Ass(es). (Now don't get upset with me. The word ass is in the Bible. It means donkey. Now what were *you* thinking?) But I digress.

Time would never permit me to list the multitude of events and gatherings that truly deserve to be shamed by this exposé so I have selected one to serve for all. (All of these events are pretty much the same anyway. Just change the location and date).

About three years ago, I was invited to attend (as in not invited to speak) a meeting, conference, symposium, get-together, training of trainers (whatever) in the lovely city of San Diego, California. Subject: FASD. I had heard that National Trainers were going to be selected from those in attendance, so I was interested. As I am the single parent of an adult child who has FASD and the owner of a small dog, I made out-of-pocket arrangements to pay the expenses to have them cared for while I was gone. So I drove the three-hour trip to the closest airport, parked my little car and headed off to what from this point on, would be my all-expense-paid adventure.

For the next two nights and three days I had never seen such extravagance! Lavish hotel SUITES. Exceptional GOURMET buffets. The ultimate in meeting rooms and

technical support services. First class all the way! There were reams of printed literature piled high on side tables, passed out individually and stuffed into folders and huge three-ring binders. And, by the way, could someone please explain why it seems to be necessary for a speaker to burden each audience member with a stack of printouts of the boring typewritten power-point presentations which they have just finished monotonously reading to the room?

What an unconscionable waste of money, time and resources! With the taxpayer money that grand shin-dig cost in hotel rooms, airfares, taxis and all the other pomp and circumstance, they could have built a brand new group home, staffed it and finally let some of those millions upon millions of taxpayer dollars HELP children with FASD instead of getting together to talk about it, again and again.

Sort of like the interagency coordinating council meetings we all attend across the country. What a joke! There they are, all dressed up in their navy blue suits, having driven the company car or being reimbursed for the mileages and per diems and interrupting the chatter just long enough to generate another flip chart and set the time and date for the next month's carbon copy meeting. So the golden Ass Award goes to the federal administrators and small town clowns who play "Spin the Syndrome" for fame and fortune and turf and title.

The moral of this little story is that FASD is not an industry. It's all of the children like my precious son, Danny, who has a tragic birth defect that I cannot fix.

As a birth mother who is constantly aware that I ignorantly drank alcohol during my pregnancy, I would like to end these Awards with a challenge to private, state and federal agencies. This is a preventable disability, so let's prevent it! I believe it is of the *utmost importance* that FASD prevention education be a mandatory and comprehensive component of every middle school and high school health program, as well as every alcohol and/or drug rehabilitation program for people of any age.

Truly, the best and most cost-effective intervention is prevention—not only in terms of tax dollars but in quality of life for everyone. ♥

Neurofeedback and My Vision for the Future

Kenneth Dunning, M.S., L.M.H.C.
(360) 391-3910; consultkdms@verizon.net



It's hard to believe this is the last issue of *FAS Times*. I'm finding myself having to work hard at updating my thinking about communication and the possible benefits and real advantages of "blogging" for FAS*FRI and for all of us.

For myself, I decided to use this space to share a little update on what I've been doing. Neurofeedback is still a valuable therapeutic tool for individuals with FASD (and their family members/caregivers). However, things in this arena have evolved with time, so that quality neurofeedback equipment and software are now dramatically reduced in price. A lot of the technical skill a therapist used to bring to the neurofeedback session is no longer necessary because most (perhaps all) current neurofeedback programs can do a lot of self-adjusting.

This is not to say that time with a trained neurofeedback therapist isn't valuable. But a lot can be done in the home, where professional equipment can be used by parents who have the commitment to learn the basics and stick with it. Partially for these reasons, I have closed my neurofeedback office and I'm currently providing general consultation around FASD. Also I'm offering training in the use of neurofeedback equipment to those who want to learn to work with it in their own homes.

The biggest challenges I see currently facing the FASD community are the development of therapeutic, educational, vocational, and ongoing life support resources tailored to those with FASD. A lot of public and private funding is being spent on "hand-me-down" therapies, interventions, curricula and educational plans that have shown efficacy with other conditions, but are of marginal value at best with individuals with FASD. This results in life outcomes that are not as positive as could be possible with more thoughtfully tailored resources.

We need to refocus our attentions on long term needs, including not only tailored therapeutic interventions and educational programs, but also the development of living "contexts" that are tailored to adults with

FASD. By this I am referring to group living situations, possibly apartment-type living with support staff, combined with small businesses/industries that can employ the clients and help financially support the facilities. These aren't pipe dreams—they are realities that are within our reach with commitment, organization, planning and support. It is both desirable and possible to develop living "contexts" in which affected individuals not only can survive but can be productive and build self-esteem while working toward self-sufficiency.

*Ken has served on our FAS*FRI Board since 1993 (most of that time as the only male member—what a brave man). He is a Licensed Mental Health Counselor, currently working in Mt. Vernon, WA., who has worked with many individuals with FASD and their families. His intimate familiarity with FASD originates in his having a half-brother who Ken is certain was alcohol affected, although a medical diagnosis was never sought. His brother passed away in 2005 at the age of 67. This relationship afforded Ken a close look at the long-term plight of an adult with FASD and it has given him first-hand experience of the value of the increasing knowledge we are compiling about the challenging realities of FASD. ♥*

I Couldn't Believe Them!

They Laughed About Their Children's Outlandish Behavior!

Karin Linderth Reep, MA, LMFT

With the news that this summer's edition of *FAS Times* will be the last, I feel like I'm losing my favorite National Public Radio station. I'm struggling to stave off beginning the mourning process for *FAS Times* since the issues written to date will live on, and there is a reincarnation of sorts with the planned launch of The Family Preservation Blog. But, oh how I cheered each and every time I received my copy of *FAS Times*, the collective voice of families who are affected by a member's alcohol related neurological

disorder. Their stories, for me, have always provided the *real* face to Fetal Alcohol Syndrome, the disorder described, named, and diagnosed by the medical community, and tracked by researchers, but lived by families and communities.

As a graduate student in Pacific Lutheran University's Marriage and Family Therapy program in 1991, my curiosity was triggered while listening to a short presentation about FAS in my Human Development course. This led to my thesis work: *Families of Children With Fetal Alcohol Syndrome/Fetal Alcohol Effects: Experiences With Service Providers*. After reading Dr. Sterling Clarren's descriptive articles and as much of Dr. Ann Streissguth and associates' research as I could find, I realized I was missing the parents' perspective of what it was like to parent affected children.

Then the stars, literally, aligned. I was in Tacoma; the University of Washington was in Seattle. And Jocie DeVries was creating a community for families raising children with this disability. Our fearless leader became a spokesperson, FAS*FRI was formed, and the collective voice would not stop telling it like it *really* is. Through my association, and then friendship, with Jocie, Vicky, Ann, and Linda (and many others like Hartley Beeler) I learned...after the tears and exhaustion they had to laugh and share their stories to process their grief and make sense of the senselessness of their children's behaviors. It was through FAS*FRI that I met the parents who allowed me to interview them for my research.

I am forever grateful to them, especially for what I have learned from the parents and families raising children who have ARND. I believe my family systems' perspective broadened when I listened and learned from the families I interviewed, and from families I have seen in my therapy room over the last 14 years. My FAS*FRI board member privilege has entitled me to vicariously go places other therapists have not. Spotting ARND behavior problems when a family presents for help I believe has saved children and families a lot of time in seeking appropriate services. And I owe it to The Pest of the West entourage.

Karin has served on our Board since the mid-1990's. She is a licensed marriage and family therapist and a Neurofeedback trainer. Her offices are in Redmond/Bellevue and Duvall, WA. She can be reached at: (425) 788-9921. ♥

Evolution of a Don Juan

D. Vernon Gore

I'll begin with a question. What are some of the most significant and endearing events we look forward to throughout our lives? They would probably include birth of a child, wedding day (sometimes in that order), high school and college graduation, hitting the lottery, mother-in-law moving out of your house. All these are great. However, after my graduation and being a grease monkey, I spent time in the army, five years in trucking, and 23 years in the Navy, raising four kids of my own lineage and a ridiculous number of other guys' kids due to death or abdication of their responsibilities as dads for various reasons. I was soooo looking forward to another milestone-as most of us do as we begin to enter our golden years. And that happy event is... (Drum roll please)...**retirement!** Think: motor home, winters somewhere warm and sandy, spending time with friends, new and old, and for myself-what else but another Harley.

Yes, I did retire from the Navy in 1985. Single then, again, for a few months I was living the good life. My own little house in the country back east, dating lots of pretty women. Had my sights and savings set on buying an even prettier Harley. Handsome as I was back then (and still am of course) I was so in demand by the ladies. And charming; you have no idea how much so. Which really presents a quandary: if I'm so dog-gone great of a guy, how come my hangovers lasted longer than some of my marriages? But I digress.

Georgia and I met in early 1986, got married about an hour and a half later, moved to Washington State that summer, bringing my black lab and her two teenage sons with us. Life was good. Still no R.V. or Harley yet, but they were just about to become a reality. Then I got stupid. Georgia's youngest was getting ready to graduate and enter the Navy. Eldest son was already in the Navy. For some reason, which still is unclear to me, I suggested to Georgia we do something worthwhile like *get into foster care*.

What was I thinking?!

Later, I looked back on that statement as a moment of insanity. But then again, I was

fairly certain that the State of Washington had plenty of young foster parents so they would not really need us older folks for duty. You would think that for a guy who had been around the block a few times in life that I wouldn't have been so naïve or uninformed. Think again. I must have been a few bricks shy of a load at that point. One day, after weeks of filling out forms, taking classes and all things that unsuspecting, well-intentioned people do to become foster parents, two nicely mannered and well-dressed caseworkers arrived at our abode to perform our final home study inspection.

In retrospect, if I would have known what lay ahead as the result of a passing grade, I would have positioned myself in the hot tub sipping mai-tais with a half dozen scantily clad women of questionable employment records. As it was, a short two hours after the caseworkers gave us a passing grade, we were honored by the Division of Children and Family Services (DCFS) entrusting us with the care of two toddler brothers.

I wanted to run away. This cannot be happening...late night feedings, diapers, incessant crying. Please, Uncle Sam, draft me again! But alas, returning to military service was not to be. DCFS now firmly had Georgia and me in their grasp. By the ones and twos more than a dozen little ones came and went and strangely enough, I found myself getting attached to each one of them. I was a daddy to a needy baby or toddler again. Even thought it was not my will at first, it surely must have been God's will. And Georgia was the earthly saint who advocated for each of them, sometimes even after they were suddenly taken from us.

As with all children there are many yet untold stores for each of the precious ones placed in our care. But for two of the babies we received, their life escapades continue to be played out each day in our home. Yes, seventeen years ago we adopted a little boy and a little girl who were born the same year. To attempt to tell their stories would require a myriad of articles and most of you who are raising one or more children with FASD are already well aware of the difficulties, joys and frustrations of being a parent or caregiver who has to be available for them 24/7/365.

Where are the birth dads?

Now when I say most of you, it appears to overwhelmingly be the women who have hung in there and accepted the responsibility to raise her child or to care for someone else's little one. Too often the birth dad could care less. He's had his roll in the hay. So his brief escapade has resulted in a pregnancy. So what? Not your problem-right, guy?! You're off to your next night of partying and to your next conquest. Contributing to a woman's pregnancy does not make you a dad. Being there for the child throughout his/her life is the basic requirement to qualify as a father.

So if I had a forum to talk to young men in this situation, I'd say, "Hear this, guy: there is a day coming when you will be held accountable for not only what you've done, but for what you haven't done in this life. It's called the sin of omission. However, the good news is that in spite of your neglecting your child, God loves you. And your child might even learn to love you if you will step up to your responsibilities and provide the support your child and his/her mother may need if they even want you in their lives. If the child doesn't want any contact with you-tough stuff. You brought it on yourself through your selfishness, verbal or physical abuse, abandonment or whatever you may have done or didn't do for them. Most likely its too late to make amends because they have figured out how to get along-for better or worse-without you. However, there is always tomorrow if God grants you more time on earth.

"So man up! Get your act together. Do right in any future love relationship and any child you may be blessed with. The clocking is ticking, guy. Make yourself a promise to do better this time ... yes, it will be tough. Life is. Especially when it comes to raising kids, but you can be confident that you are finally man enough to become a *real* dad. And who knows, perhaps the child that you are finally mature enough to take responsibility for, will be there for you someday when you need it the most. It'll sure beat being all alone, when the chimes are striking midnight." ♥

\$25 Million...

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bigger federal and state bureaucracies. This failure for FASD was evidenced in the amount of turnover in state personnel for the BFSS meetings in the past two years. The Center administration unfortunately chose to ignore the primary recommendation from the regional Town Hall meetings to support community/family-run networks that were already established. Had the dollars been spent at least in part to strengthen established community/family networks, these dedicated volunteers would have increased and would continue working in their communities to bring awareness and education with commitment that extends beyond funding, as they have been doing for many years.

- The administrative costs paid to Northrop Grumman are excessive, ridiculous, and a waste of taxpayer dollars. The language of the FASD Congressional [legislation] has been subverted or ignored by SAMHSA and the FASD Center for Excellence.
- Members of the Steering Committee, as well as the Expert Panel, have had no ability to set or alter the course set out by the FASD Center for Excellence administration. I will no longer take part in creating and expanding an FASD industry for a few professional careers with no benefit or support to the actual victims of FASD and their families.
- The treatment of the lifelong representative of FASD [at the meetings] is appalling. His suggestions are dismissed, and consideration of his suggestions is patently condescending. It is obvious he is the token victim for the FASD Expert Panel and I choose not to be a part of it. ♥

Jocie's Tributes...

Continued from page 5

seeing her, Jocie knew Chelise. I cried. I was so thankful, so surprised. It felt good to be taken seriously, to know there were allies out there. I was overwhelmed.

Jocie sent some material, I devoured it. She told me our children need advocates and that's US!! She gave me Dr. Clarren's name and number. She gave me hope and a safe place to go. During the next 18 years I sought comfort and information from FAS*FRI. I've attended seminars that FAS/FRI has offered. I

have talked to these amazing women and they have always been there for me. I have been given encouragement, strength, humor, love, acceptance—all these things. Through Jocie's search to provide the best life possible for her children, she has given so much to all of us.

Thanks for all the years, Jocie. You are such an inspiration and just so "real."

Love,

Sydney Platt & Chelise Boren

I have known Jocie for almost 10 years. I know her to be tenacious, caring, knowledgeable, committed, and thoughtful. She is not one to give up, as she has shown with her battle with cancer. Even when faced with cancer, she has kept her sense of humor and positive outlook, which has helped her more than any medication ever could. The FASD field will miss Jocie – but I have a feeling we will continue to benefit from her wisdom.

Sue Green

Contract Manager, DSHS/DASA

Jocie and I met in September of 1992 when she and I were both speaking at the unveiling of Ann Streissguth's Secondary Disabilities Study.

We both had sons with an FASD. My son was diagnosed at birth while hers was not diagnosed until his teenage years. We were both trying desperately to help parents who were new to the world of prenatal alcohol exposure. We both sought to prevent that lonely isolation when you are sure that no one else in the whole wide world has experienced what you and your child are experiencing. And even worse is the feeling that none of the professionals, be they teachers, doctors, or therapists know as much about it as we do. The very people we thought could guide and assist us, DIDN'T GET IT.

Our shared experience ended there, for the most part, as having a diagnosis at birth had helped our family and not having that diagnosis had hurt Jocie's family. Her hurt, disappointment, and anger were channeled into moving mountains and advocating like no other. The Pest of the West was tireless in her efforts to wake up the world—a sleeping giant that appeared to care less about children who had their first drink before they took their first breath.

Jocie and I have not always agreed on our approach, but we have always shared the same vision and passion. I have been privileged to walk with her so many times through these sixteen years, laughing, crying, and

praying, advocating and teaching. FAS*FRI has and will continue to be a vital resource for families and professionals, shining their light on the path so that other families will not need to stumble in the darkness.

Thank you, Jocie. You have attempted and succeeded. For those goals still to be achieved, you have mentored others who have joined our small band of Velveteen Rabbits. Thanks for being REAL.

Hugs and Hugs again,
Barb W.

A few years ago, a group of women formed an online support group for raising kids of various ages, all affected by prenatal exposure to alcohol. All of us had previously had bad experiences in other online groups; but it is so very hard to raise our kids alone or in a vacuum, so we gave it another try. The group started to gel and we each learned from one another's experience.

At some point, someone suggested asking Jocie Devries to join our deliberately small group. As we opened our arms to include her, she opened her arms to support us with her huge heart and vast storehouse of knowledge and life experience. It was as if we had known her forever. She is funny and wise, caring and open. She is a grandma, a mother and a sister to all of us and we adore her. She has provided a path for those of us with young children to follow and she let us share her burden on days that were the most black and full of storm clouds.

The gifts she has given us with her insight into the world of FASD are immeasurable. Periodically, as a group we say what an honor it is to be a part of this band of moms and caregivers, and it honestly is, but it has become so in large part due to the giving nature of people like Jocie that we know what works and what doesn't and where to turn for help. We are all most honored to have her be one of us and to share her life with us. We are all so much richer for sharing with her, as are all of our children. She is a special person and her life has made so many other lives fuller and more meaningful.

Thank you, Jocie, from the women of FASD Family. Thank you. Tyla S. ♥

Check It Out!

The Long Way to Simple

New Book by Stephen Neafcy

[www.betterendings.org/
libertyridgemedia/simple.htm](http://www.betterendings.org/libertyridgemedia/simple.htm)

Our Board: People of Commitment & Loyalty

Jocie DeVries

Vicky McKinney, Linda La Fever, Ann Waller and I have been the primary staff writers of *FAS Times* since its inception in February 1992. I feel compelled to give special tributes to these three women. I believe it is past time that I retire and Vicky be promoted to Executive Director of FAS*FRI, but she adamantly says no—that we are a team and we are going to say that way. So I humor her. Although I started the “phone line” in 1991, the main person who has kept it going the last 13 years is Vicky. That is where she gets her constantly updated data—from the front lines of the Collective Family Experience and that is why her advocacy is so effective. And the most fascinating thing of all is that she possesses the deepest reservoir of mercy of anyone I have ever known.

Most people don’t know this, but I actually resigned as Executive Director of FAS*FRI once upon a time. But my announcement created a small riot within the board. Vicky and Ann insisted on meeting with me before the Board meeting. I was trying to nominate Ann as Executive Director because she had just finished her Master’s Degree. Ann said she was honored, but she didn’t have the administrative skills I have, so she and Vicky grilled me as to why I wanted to resign. Tearfully, I admitted I didn’t have the educational background to continue leading FAS*FRI. Ann then asked what kind of help I would need to feel comfortable enough to stay on as director. I told her I really needed help with formal letters, reports, etc. So Ann committed her time, writing talents, her ever-so-patient editorial skills and her computer expertise, if I agreed to stay on. The most amazing thing is that Ann saw my potential and gave up “a real job” in order to make me look good.

Then there’s Linda La Fever, who has led FAS*FRI’s Birth Mom Mentor Program since 1993. She constantly amazes me with her wisdom, wit and willingness to share from the deepest levels of her heart. Linda’s greatest strength is her ability to continue to share her own journey and mentor other

birth moms, regardless of how many times she is unfairly criticized by ignorant people who don’t understand addiction. And, best of all, by the grace of God, we four have all been able to work together as a strong team.

But it is our Board of Directors of FAS*FRI that provides the encouragement that motivates us. Their commitment to build a better world for those with FASD is inspiring. The photo below of our Board was taken during our parent retreat in August of 2005.

Starting with the back row, left to right, are Ann, Susan Bradley, Dot Workman, Georgia Gore, Margie Booth, Dorthy Beckwith, me, Vicky, and Delinda McCann. On the front row is Kathy Dodson, Linda, Pam Medgard, and Karin Reep. Together we parents have over 400 years of collective experience in caring for diagnosed children. Additional Board members, who are not pictured here, include Ken Dunning, June Ettestad, Dale and Joline Clark, Jodi Hardy, Lorri Cox, Diane Davis, and Bob Crawford (who took the photo).

Since our organization began in the fall of 1990, many other special people have served on our Board and eventually moved on to other ventures including: Becky Bangsund, Sarah Brown, Roxanne Tillman, Tim Roth, Vince Collins, Naomi Peterson, Christy Con-

nors and Joeline Beeman. I would also like to thank the faithful members of the *FAS Times* Editorial Board: Vicky McKinney, Dorthy Beckwith, Dale Clark, Joline Clark, Linda La Fever, Don Gore and Sue Green.

These co-workers are all incredibly talented people. Whenever I think of any of them, my heart overflows with gratitude and love. But to me, their greatest asset is loyalty not only to me and FAS*FRI, but loyalty and unconditional love for their children, which is why their kids are doing so well. And to have them befriend me during the past eighteen years of FASD advocacy is one of the greatest joys of my life. With this—the last issue of *FAS Times*—we are all in a time of transition. We are each a little sad that *FAS Times* is coming to an end. But on the other hand, we feel a great deal of accomplishment that we have produced this great body of knowledge called the FASD Collective Family Experience.

Ahhhh, and I have to admit that I am relieved and thrilled to have more time to spend with my husband and sweetheart of 46 years, Don, and with my children and grandchildren. Remarkably, all of us at FAS*FRI are blessed to have our affected children relatively safe and happy in this troubled world and for that we are very, very thankful. ♥



FAS*FRI Board Accused...of Having Too Much Fun!

When several of us are together at meetings and conferences that can get very heated and stressful or full of grief and pain, we often gather during the breaks to regroup. Once we vent to each other, we often find something to laugh about. Many times, others observe this and it puzzles them, so all they can think to say is, “You women are just having too much fun!”

Moving Forward...

Continued from page 6

able to take off on her own without your approval and you will have no legal recourse. In some states, a youth can become emancipated as young as 14-16 years old. You can apply for legal guardianship over her as an adult. This has advantages and disadvantages, so I would advise that you discuss this with a lawyer who specializes in this type of guardianship before you make any decisions on this.

Having said all of this, none of us knows what her future will be. Her personality may be sweet and compliant and she may not meet anyone who will pull her into danger. If so, you may be able to carry out your plans for her without too many major bumps in the road.

The one thing I do know without a doubt is that the most important thing you can do for her is to love her unconditionally and let her know you will always "be there" for her. (You don't have to describe what that means in detail. ☺) And prayer

is equally important! God is amazing. He will walk with you and give you strength, wisdom and peace. All He asks is that we love Him and others and keep walking in His footsteps. The rest is up to Him.

For many years I carried the unnecessary burden of total responsibility to "make things happen" and suffered greatly when it looked like nothing I did was helping. As a result I developed stress-related illnesses and some measure of Post Traumatic Stress Disorder, which have gotten better only in the last seven years after concentrated pursuit of complimentary methods for healing and wholeness. Yes, I messed up a lot in my ignorance, but I did the best I could and God is a redeemer God even when it comes to our mistakes, if we give those to Him too. That is the most freeing thing I've learned in the last few years. Wish I'd figured it out sooner.

Eventually the Lord gave me Romans 12:12 as one of my major life verses: "Be joyful in hope, patient in affliction and faithful in prayer." This verse is one of many, but a very important one that took me a long time to really understand how to

live it. Or maybe a better way to say it is I keep learning it in different areas of my life and/or on deeper levels. Take care. Blessings, Ann

Soon after I sent it, I realized it summed up a lot of things that I wanted to tell parents in my last article for FAS Times. So here you have it.

After my responsibilities come to a close with *FAS Times*, it is my desire and commitment to go back to school to become an ordained minister and earn a PhD in Health Psychology. In this way, I will be qualified to be a "wholistic healing consultant." (I made that title up. Aren't you impressed?) I should be about done by the time most people retire. ☺

I don't intend to leave the field of FASD entirely. One of my main goals is to help parents of affected children be better equipped to handle stress and to avoid Post Traumatic Stress Disorder (PTSD). So it is with a little sadness, but much gratitude for these last thirteen years of producing FAS Times, that I move into this next phase of my life. Meet you at the Blog when I'm taking a breather from my studies. ♥

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